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Quality of Life with Breast Cancer

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FOREWORD

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PI - Signature

07/29/96

Date

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Introduction

This report summarizes activities for the second year of a four-year study. The study will develop, implement and evaluate a volunteer peer support program for women newly diagnosed with breast cancer. This program augments and complements the American Cancer Society's Reach to Recovery Program. Our primary aim is to determine the value of providing a comprehensive, organizationally-specific, peer support program to women beginning at diagnosis and continuing for up to one year. This study asks four research questions:

- (1) Does this expanded program improve (a) quality of life with breast cancer; (b) participation with treatment decisions; and (c) satisfaction with care?
- (2) How do patient sociodemographic characteristics influence these outcomes?
- (3) What are the main benefits of this program?
- (4) Does participation in treatment decisions improve quality of life?

Participants are paired (as closely as possible by age, marital status, racial/ethnic background) with a trained breast cancer survivor, or "buddy", who provides them with ongoing peer support, in addition to specific information and skills to help them navigate the Kaiser Permanente Medical Care Program. Study volunteers receive the standard Reach to Recovery training, in addition to a two-day skills training which prepares them to become breast cancer peer support volunteers ("peer supporters") and advocates.

Body: Year 2 Activities

The second year has been devoted to implementation of the peer support program. Information and feedback received in year one, in addition to experience gained as we progress, is utilized to provide the peer support intervention. Facility-specific recruitment, volunteer training and support, and overall project maintenance have comprised the heart of the second year.

Activities have included: (1) recruiting, interviewing and training volunteers at five sites; (2) providing support to volunteers; (3) training medical center staff at each site to assist project staff with recruitment; (4) recruiting participants; (5) matching volunteers with study participants; (6) developing systems of communication for project staff; and (7) developing and utilizing a computer-based system for tracking patients.

Recruitment and training of volunteers is an ongoing and essential component of year two. Volunteers are sought who, as closely as possible, match the demographics of the newly diagnosed women at each facility. We have held six 3-day trainings since August 1995 (attached is a three-day training agenda). As of June 30, 1996 we have trained forty-four volunteers, and are currently screening women for the next training to be held in August 1996. The variety of women who make up our volunteer pool is impressive. For example, women have described themselves as: proud new grandmothers, single moms, long-time Kaiser Permanente employees, kindergarten teachers, and wives of corporate executives.

It became clear to the project staff very early on that an important unintended consequence of the study was the benefit to the volunteer of participation in the project. This benefit is derived from attending both the 3-day training and the monthly volunteer meetings, as well as the experience of providing peer support. The volunteer trainings are not simply didactic presentations; they afford participants the opportunity to learn new skills through exploring their own personal experience of diagnosis, treatment and follow-up of breast cancer in order to see if there are any unresolved experiences that might get in the way of a relationship with a newly diagnosed patient. Volunteers going through the training have reported a high level of satisfaction with the training; increased self-efficacy with their decision making and problem solving skills; and a high degree of personal healing.

Supporting the volunteers takes on a variety of forms. In order to be effective in their role as breast cancer peer supporters, volunteers rely on project staff for training, information, and continuous availability for debriefing and troubleshooting. In addition to receiving assistance as needed, each volunteer attends monthly meetings where she is provided with a safe and reliable place to meet with other volunteers and project staff; discuss buddy contacts and raise questions or concerns; exchange information; and receive feedback and reinforcement. She is encouraged to share her feelings, reactions, fears, successes and perceived blunders. This structure enables the volunteer to approach her buddy--often a woman in extreme distress, uncertain and overwhelmed--from a place of personal strength and flexibility.

Participant recruitment has proven to be a stimulating challenge. It has required developing and perfecting effective recruitment procedures at five research sites--each of which has its own personality, culture, and attitudes about care delivery. Kaiser Permanente, like many other medical care institutions, is currently undergoing a period of organizational restructuring. This creates a climate in which all staff, from professional to clerical, are being required to do more with reduced resources. Therefore our project has sought ways to make as few demands on medical center staff as possible and at the same time accomplish our recruitment goals. This has required developing an ongoing process of buy-in; to accomplish this we have attended task force meetings, met with surgeons, nurses and social workers at all facilities. We have hired project staff at each facility and have attempted to work as insiders from within each facility as much as possible, building study recruitment into the structure of each workday.

The recruitment process involves the following steps: Each week project staff (1) obtain names of newly diagnosed breast cancer patients from the pathology departmental each medical center; (2) identify eligible patients for the study; (3) obtain permission from the eligible patients' surgeons to send out the study invitation packet (which includes an invitation letter describing the project signed by the patient's surgeon, a baseline questionnaire and consent form to be returned if interested in participating in the study); (4) mail the invitation packet; and (5) if we have not received the questionnaire and consent form--make one follow-up telephone call seven days after the letter is mailed to answer any questions and/or to send another invitation packet if needed. Inasmuch as the time immediately surrounding the diagnosis of breast cancer is an extremely emotional one in which many decisions have to be made, patients appreciate a gentle reminder

about the study and an opportunity to talk about it with project staff. They often report to us that they placed the invitation packet at the bottom of a pile to be dealt with after the most pressing issues are handled and are glad we called.

Since beginning patient recruitment in October 1995 through June 30, 1996 we have recruited 76 patients into the study. Our original recruitment goal of 28 patients per month was unrealistic in the first months of recruitment for a several reasons. In large part due to Health Plan organizational changes, it took us longer than anticipated to develop recruitment systems that worked effectively at each facility. These are now in place and functioning efficiently at all facilities as evidenced by the fact we recruited 25 patients in July. We originally believed we could meet our recruitment goals conducting the study at four medical centers. In order to have a larger enrollment pool we added a fifth medical center--with all the recruitment training and physician buy-in that that entails.

If we maintain the level of recruitment currently achievable and continue recruitment until June 1997 we estimate we will have a final sample size of at least 376 women. If we are able to further fine tune the system, we may come closer to our original recruitment estimate. Nevertheless, our project biostatistician has concluded that our reduced numbers will not produce a dramatic change in the minimum detectable difference for our outcome measures. Our original sample size of 250 in each study group was estimated to provide sufficient power (80%) to detect a .25 standard deviation unit difference in the mean of each measure of effectiveness, using a two-sided Z-test and significance level = .05. A reduced sample size of 150 in each study group will provide sufficient power to detect a .32 standard deviation unit difference in the mean of each measure of effectiveness. This represents a 28% increase in the minimum detectable difference. A sample size of 175 in each study group will provide sufficient power to detect a .30 standard deviation unit difference in the mean of each measure of effectiveness.

We have developed a data tracking system using a Paradox database. We have entered all study participants into this database and are able to track the due date for the completion of three-month and ultimately one-year follow-up questionnaires. As of June 30, 1996 we sent out 30 three-month questionnaires (followed up with a post card and a second questionnaire and phone call as needed) and to date 28 have been returned. We also use the Paradox database to record the names of the volunteers who are matched to each patient and are able to see at a glance which volunteers are available for new patients.

Conclusions

The second year has been spent implementing the intervention (including recruiting, training and supporting volunteers); establishing effective patient recruitment systems; and in recruiting patients. We will continue these activities in year 3. We begin data collection for the one-year follow-up in October 1996.

**American Cancer Society Reach To Recovery Training
Breast Cancer Peer Support Volunteer Project
Friday, May 3, 1996
Kaiser Permanente Medical Center-Santa Clara
Conference Room E &
Special Conference Room
(ground floor of hospital)**

- 8:45-9:00** **Registration**
- 9:00-10:15** **Welcome and Introductions** **Beth Eshelman, LCSW**
 Overview of the Breast Cancer **Breast Cancer Project Coordinator**
 Peer Support Project
- 10:15** **Break**
- 10:30** **Breast Reconstruction Video "A Sense of Balance"**
- 11:15-12:00** **Nancy Bitar, M.D.**
 Department of Surgery, Santa Clara
 Breast Cancer Diagnosis and Surgical Procedures
- 12:00** **What it means to be a Kaiser Volunteer**
 Barbara Turley, Assistant Volunteer Director, Santa Clara
 • Kaiser Permanente Volunteer Policies, Benefits and Procedures
- 12:30-2:00** **Lunch in Central Park**
- 2:00-2:30** **Raji Ayyar, MD**
 Department of Oncology, Santa Clara
 • Chemotherapy and coping with side effects
- 2:30** **Break**
- 2:40** **American Cancer Society Reach to Recovery Program**
 Donna O'Neill, Reach to Recovery Coordinator
 Silicon Valley/Central Coast Region

 • Overview of Reach to Recovery Program
 • The Reach to Recovery Visit
 • ACS Programs: Look Good Feel Better, Special Touch,
 Transportation, Resources
- 4-4:30** **Wrap-Up/Evaluation and Coming Attractions**

Breast Cancer Peer Support Volunteer Project
May 4, 1996
Kaiser Permanente Medical Center-Santa Clara
Building K: Conference Room, 2A

| | | |
|--------------------|--|---|
| 9-9:30 | Welcome and Introductions <ul style="list-style-type: none">* Check-in | Beth Eshelman Shelia Kennedy |
| 9:30-11:00 | Psychological Issues <ul style="list-style-type: none">• Value Clarification• Crisis/Loss/Change• Coping Styles and Skills• Dealing with Emotional Reactions• Reactions of Family and Friends | Beth Eshelman |
| 11:00-11:15 | Break | |
| 11:15-12:15 | Body Image & Sexuality <ul style="list-style-type: none">• Hormonal and psychological effects of breast cancer | Beth Eshelman |
| 12:15-1:15 | Lunch | |
| 1:15-2:30 | Communication Skills <ul style="list-style-type: none">• Listening Skills• When to listen, when to respond. | Sheila Kennedy |
| 2:30 | Break and Stretch | |
| 2:45-4:15 | Communicating with Your Health Care Team <ul style="list-style-type: none">• Informing and taking PART | Sheila Kennedy |
| 4:15 | Wrap-up and Coming Attractions | |

Breast Cancer Peer Support Volunteer Project
May 10, 1996
Kaiser Permanente Medical Center-Santa Clara
Building K: Conference Room 4A

| | | |
|-------------------|---|--|
| 9-9:30 | Check-in/Review Day | Beth Eshelman |
| 9:30-10:30 | Problem Solving Skills <ul style="list-style-type: none"> ◊ Empowering your buddy ◊ Problem Solving Skills ◊ When and where to get help | Hannah Wedgley Research Assistant |
| 10:30 | Break Navigating the Kaiser Permanente Medical Care Program <ul style="list-style-type: none"> • Accessing the information and support needed • Role of Volunteer | Beth Eshelman Jackie Green, LCSW |
| 12:30-1:15 | Lunch | |
| 1:15-2:30 | Decision Making Skills <ul style="list-style-type: none"> • Decision making during a crisis • Role of the volunteer | Beth Eshelman |
| 2:30 | Break | |
| 2:45-4:00 | Self Care Skills Caring for Yourself and for Your Buddy. <ul style="list-style-type: none"> ◆ Making healthy lifestyle choices: exercise, diet, relaxation ◆ Techniques and Resources | Beth Eshelman Hannah Wedgley |
| 4:00-4:30 | What is next? Wrap-Up/Evaluation <ul style="list-style-type: none"> • Bi-monthly meetings; Post training interviews • Continued education: what other topics would you like to have covered? • Evaluation | Beth Eshelman |

Peer Support Volunteer Meeting
Kaiser Permanente Medical Center, Oakland
June 20, 1996
6:00-7:00 PM

Agenda

1. **Lynn Brissette, RN, Oakland Breast Care Coordinator**
 Introduction to group
 Her role with the project
2. **Project Update**
 Recruitment numbers for all five facilities
3. **Personal check-in**
 How has this month been?
 Upcoming vacations, etc.
4. **Patient reports**
 How's it going?
 Update the group on what's happening with you and your buddy
5. **Topic: Death and Dying**
 Handout tapes for everyone to listen to if they it would be useful
6. **Handouts**
 Volunteer Feedback Questionnaires

Please answer the following questions and return the survey in the enclosed prepaid, self-addressed envelope. **All the information you provide in the survey will be kept completely confidential.** Your answers will not be shared with your doctor or employer, become part of your medical record, or affect your Health Plan membership or dues.

1. Overall, how would you rate your current understanding of breast cancer and its treatment?

1 ☐ Poor 2 ☐ Fair 3 ☐ Good 4 ☐ Very good 5 ☐ Excellent

2. How important is each of the following types of information to you:

| | Not Important 1 | Somewhat Important 2 | Important 3 | Very Important 4 | Essential 5 |
|---|--------------------------|----------------------------|--------------------------|--------------------------|--------------------------|
| a. Simple and clear explanations of technical and medical terms | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Articles from scientific or medical journals about breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. What are the expected results of each treatment option | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Information about how breast cancer can be spread | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Examples of cases where the treatment has not been effective | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Why a particular treatment option is or is not appropriate for me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. What are the possible side effects of treatments(s) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Statistical information about how likely it is that I will benefit from a particular treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Statistical information about how likely I am to have a recurrence | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. Information about how others in my situation dealt with their breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. What my doctor believes is the best treatment for me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3. Check the sentence that best describes your point of view:

- 1 ☐ I want **only** the information needed to treat my breast cancer.
 2 ☐ I want additional information only if it is **good** news.
 3 ☐ I want as **much** information as possible, good or bad.

4. To what extent do you agree or disagree with each of the following:

| | Disagree Strongly 1 | Disagree Somewhat 2 | Agree Somewhat 3 | Agree Strongly 4 |
|--|---------------------------|---------------------------|--------------------------|--------------------------|
| a. I usually ask my doctor a lot of questions. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I have difficulty getting emotional support from my doctor (getting my doctor to understand my feelings). | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

5. Check the sentence that best describes your point of view:

During a medical care visit, if a doctor or nurse practitioner says something that I don't agree with:

- 1 ☐ I have never or rarely disagreed with a doctor.
 2 ☐ I usually let it pass.
 3 ☐ I talk to someone else about it.
 4 ☐ I talk directly to my doctor and let him or her know what I think.

6. How often do you do each of the following?

| | Never 1 | Sometimes 2 | Often 3 | Always 4 |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Prepare a list of questions in advance when you visit your doctor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Discuss with your doctor any personal problems that may be related to your illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Discuss any problems you had following a treatment plan, such as taking a medicine or following a special diet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Call your doctor(s) between visits if you have problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7. After they have all the information they need about their illness and possible treatments, some people prefer to leave the final decisions about their treatments to their doctors, while others prefer to participate in making these decisions.

Which statement best describes what you believe would be ideal?

- 1 ☐ The doctor(s) should make the decisions using all that is known about treatments.
2 ☐ The doctor(s) should make the decisions but strongly consider my opinion.
3 ☐ The doctor(s) and I should make the decisions together on an equal basis.
4 ☐ I should make the decisions, but strongly consider the doctor's opinions.
5 ☐ I should make the decisions using all that I know or learn about the treatments.

8. To what extent do you agree with the following statement:

"You should go along with the doctor's advice even if you disagree with it."

- 1 ☐ I agree strongly 2 ☐ I agree somewhat 3 ☐ I disagree somewhat 4 ☐ I disagree strongly

9. How many relatives and friends do you have that you feel close to (relatives and friends that you feel at ease with, can talk to about private matters, can call on for help)? (Check one box for relatives and one box for friends.)

| | Relatives | Friends |
|------------|-----------|---------|
| None | | |
| 1 or 2 | | |
| 3 to 5 | | |
| 6 to 9 | | |
| 10 or more | | |

DEMOGRAPHIC INFORMATION

The information from these last questions will help us better understand the needs of our different patients. No names or other identifying information will ever be used.

10. What is your date of birth?

____/____/____
month date year

11. What is the highest level of school you completed?

- | | |
|--|---|
| 1 <input type="checkbox"/> 8th grade or less | 4 <input type="checkbox"/> Some college or technical school |
| 2 <input type="checkbox"/> 9-11th grade | 5 <input type="checkbox"/> Completed 4-year college (e.g. BA, BS) |
| 3 <input type="checkbox"/> 12th grade (high school graduate/GED) | 6 <input type="checkbox"/> Completed graduate degree |

12. What is the your race or ethnicity? (You are encouraged to check all that apply.)

- | | |
|--|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Hispanic/Latina |
| <input type="checkbox"/> North American | <input type="checkbox"/> Mexican American or Chicana |
| <input type="checkbox"/> European | <input type="checkbox"/> Puerto Rican |
| <input type="checkbox"/> Middle Eastern | <input type="checkbox"/> Cuban |
| <input type="checkbox"/> North African | <input type="checkbox"/> Central or South American |
| <input type="checkbox"/> Other (please specify: _____) | <input type="checkbox"/> Other (please specify: _____) |
| <input type="checkbox"/> Black or African American | <input type="checkbox"/> Asian or Pacific Islander |
| <input type="checkbox"/> US Black or African American | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Caribbean | <input type="checkbox"/> Filipino |
| <input type="checkbox"/> Central or South American | <input type="checkbox"/> Korean |
| <input type="checkbox"/> North African | <input type="checkbox"/> Japanese |
| <input type="checkbox"/> Sub-Saharan African | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Other (please specify: _____) | <input type="checkbox"/> Asian Indian |
| | <input type="checkbox"/> Other (please specify: _____) |
| <input type="checkbox"/> Native American or Indigenous People | |
| <input type="checkbox"/> North American Indian | |
| <input type="checkbox"/> Eskimo | |
| <input type="checkbox"/> Aleut | |
| <input type="checkbox"/> Native Hawaiian | |
| <input type="checkbox"/> Native Samoan, Guamanian, or other Pacific Islander | |
| <input type="checkbox"/> Other (please specify: _____) | |
| <input type="checkbox"/> Other (please specify: _____) | |

13. Do you consider yourself to be multi-racial or multi-ethnic? 1 ☐ Yes 2 ☐ No

14. What is your current marital status?

- | | |
|---|--------------------------------------|
| 1 <input type="checkbox"/> Single | 4 <input type="checkbox"/> Divorced |
| 2 <input type="checkbox"/> Married | 5 <input type="checkbox"/> Separated |
| 3 <input type="checkbox"/> Domestic Partner | 6 <input type="checkbox"/> Widowed |

15. What is your sexual orientation?

- 1 ☐ Heterosexual 2 ☐ Lesbian 3 ☐ Bi-sexual

16. Which of the following best describes your living arrangement? (Check only one answer.)

- 1 ☐ Live alone
2 ☐ Live with partner, family, or friends
3 ☐ Other

17. What is your current work status?

- 1 ☐ Working full-time (35 hours or more per week)
2 ☐ Working part-time (less than 35 hours per week)
3 ☐ Homemaker
4 ☐ Student
5 ☐ Temporary medical leave
6 ☐ Permanently disabled
7 ☐ Retired (e.g. not currently employed and not looking for work)
8 ☐ Not currently employed and looking for work

18. If you have ever worked outside the home (please print):

a. In what kind of business, industry, profession or occupation have you usually worked?

b. What has been your usual job title?

c. What have been your most important duties or activities? That is, what have you actually done at your usual work?

19. What is your religious background?

- | | |
|-------------------------------------|--|
| <input type="checkbox"/> Protestant | <input type="checkbox"/> Buddhist |
| <input type="checkbox"/> Jewish | <input type="checkbox"/> Other (please specify: _____) |
| <input type="checkbox"/> Catholic | <input type="checkbox"/> None |
| <input type="checkbox"/> Muslim | |

20. How important is *organized religion* in your life?

- ☐ Very important
☐ Somewhat important
☐ Not very important
☐ Not at all important

21. How important is *spirituality* in your life?

- ☐ Very important
☐ Somewhat important
☐ Not very important
☐ Not at all important

22. Do you speak a language other than English in your home? ☐ Yes ☐ No

If YES:

a. What language do you prefer?

- ☐ Spanish ☐ Tagalog ☐ Cantonese ☐ other (please specify: _____)

b. How comfortable do you feel in speaking English at the doctor's office?

- ☐ Very comfortable
☐ A little comfortable
☐ Not at all comfortable
☐ Other (please specify: _____)

Name (Please Print) _____

Address _____

Telephone Number (____) _____ - _____ Medical Record Number _____

Thank you for completing the questionnaire. Please return it in the pre-addressed, postage-paid envelope to:

**Sheila Kennedy, MA
Division of Research, Kaiser Permanente, P O Box 12916, Oakland, CA 94604-9921**

BREAST CANCER PEER SUPPORT PROJECT THREE MONTH QUESTIONNAIRE

Please answer the following questions and return the survey in the enclosed prepaid, self-addressed envelope. **All the information you provide in the survey will be kept completely confidential.** Your answers will not be shared with your doctor or employer, become part of your medical record, or affect your Health Plan membership or dues.

1. Overall, how would you describe the care you received at Kaiser Permanente to diagnose and treat your breast cancer?

1 ☐ Poor 2 ☐ Fair 3 ☐ Good 4 ☐ Very good 5 ☐ Excellent

BREAST CANCER TREATMENT

2. Which of the following treatments have you had or do you plan to have?

| | Had in past/ having now 1 | Plan to have 2 | Do not plan to have 3 | Undecided 4 |
|---|---------------------------------|--------------------------|-----------------------------|--------------------------|
| a. Mastectomy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Lumpectomy (breast conserving surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Breast reconstruction | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Radiation therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Chemotherapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Tamoxifen (hormonal therapy) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

3. Were you interested in obtaining a "second opinion" with another surgeon to discuss your treatment options?

1 ☐ No 2 ☐ Yes, and I got one. 3 ☐ Yes, and I didn't get one.

4. Once at home, how prepared were you to do the following?

| | Not at all prepared 1 | Not very prepared 2 | Somewhat prepared 3 | Very prepared 4 | Does not apply 5 |
|-----------------------------------|-----------------------------|---------------------------|---------------------------|--------------------------|--------------------------|
| a. Care for the drain | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Perform arm exercises | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Know the signs of infection | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Deal with any pain or numbness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

5. How useful did you find the following breast cancer resources and services?

| | Very useful 1 | Somewhat useful 2 | Not Very useful 3 | Not at all useful 4 | Did not use 5 |
|--|--------------------------|--------------------------|--------------------------|---------------------------|--------------------------|
| Kaiser Health Education materials (pamphlets, videos, etc.) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Shared Decision Making video for breast cancer surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Shared Decision Making video for breast cancer adjuvant treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Kaiser psychiatrist, psychologist or psychiatric social worker | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Breast Care Coordinator | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| American Cancer Society Reach to Recovery Program | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Kaiser peer support program | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Support group for women with breast cancer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Educational and support services for family and friends | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other _____ | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

DECISION MAKING

6. How were the decisions made regarding your surgery for breast cancer, that is, whether to have mastectomy or lumpectomy?

- 1 ☐ The doctor(s) made the decisions
- 2 ☐ The doctor(s) made the decisions but considered my opinion
- 3 ☐ The doctor(s) and I made the decisions together on an equal basis
- 4 ☐ I made the decisions, but strongly considered the doctor's opinions
- 5 ☐ I made the decisions using all I knew or learned about the treatments that were available

7. How were the decisions made regarding any additional (adjuvant) therapy you considered, such as chemotherapy or Tamoxifen?

- 1 ☐ The doctor(s) made the decisions
 2 ☐ The doctor(s) made the decisions but considered my opinion
 3 ☐ The doctor(s) and I made the decisions together on an equal basis
 4 ☐ I made the decisions, but strongly considered the doctor's opinions
 5 ☐ I made the decisions using all I knew or learned about the treatments that were available

8. To what extent do you agree with the statement: "You should go along with the doctor's advice even if you disagree with it.":

- 1 ☐ Strongly disagree 2 ☐ Disagree 3 ☐ Agree 4 ☐ Strongly Agree

9. To what extent to you agree or disagree with each of the following:

| | Disagree Strongly 1 | Disagree Somewhat 2 | Agree Somewhat 3 | Agree strongly 4 |
|--|---------------------------|---------------------------|--------------------------|--------------------------|
| a. I understood the advantages and disadvantages of each treatment option: | | | | |
| 1. Mastectomy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Lumpectomy (breast conserving surgery) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Breast Reconstruction | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Radiation Therapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Chemotherapy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Tamoxifen (hormonal therapy) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I understood why some treatment options were not available to me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. I had enough time to make my treatment decisions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I wish I had had more information about my treatment options | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. I am satisfied with my treatment decisions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

10. I discussed my treatment options with:

| | Not at all 1 | A little bit 2 | Quite a bit 3 | A lot 4 |
|-----------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. My family | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. A close friend | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. A breast cancer survivor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. A peer support volunteer | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

11. To what extent to you agree or disagree with each of the following:

| | Disagree Strongly 1 | Disagree Somewhat 2 | Agree Somewhat 3 | Agree Strongly 4 |
|---|---------------------------|---------------------------|--------------------------|--------------------------|
| a. I usually ask my doctor a lot of questions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I have difficulty getting emotional support from my doctor (getting my doctor to understand my feelings) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. I have difficult getting the information that I need from my doctor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

12. How often do you do each of the following?

| | Never 1 | Sometimes 2 | Often 3 | Always 4 |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Prepare a list in advance when you visit your doctor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Discuss with your doctor any personal problems that may be related to your illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Discuss any problems you had following a treatment plan, such as taking a medicine or following a special diet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Call your doctor(s) between visits if you have problems | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

13. Overall, how would you rate your current understanding of breast cancer and its treatment?

1 ☐ Poor 2 ☐ Fair 3 ☐ Good 4 ☐ Very good 5 ☐ Excellent

14. Below is a list of statements that other people with your illness have said are important. By checking one box per line, please indicate how true each statement has been for you during the past 7 days.

| Physical well-being | Not at all 1 | A little bit 2 | Somewhat 3 | Quite a bit 4 | Very much 5 | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---|---|---|---|---|--------------------|
| a. I have a lack of energy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| b. I have nausea | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| c. Because of my physical condition, I have trouble meeting the needs of my family | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| d. I have pain | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| e. I am bothered by side effects of treatment | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| f. I feel sick | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| g. I am forced to spend time in bed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| h. Looking at the above 7 questions, how much would you say your PHYSICAL WELL BEING affects your quality of life? | 0 not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very much so |

Social/Family Well-Being

| | Not at all 1 | A little bit 2 | Somewhat 3 | Quite a bit 4 | Very much 5 | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---|---|---|---|---|--------------------|
| a. I feel distant from my friends | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| b. I get emotional support from my family | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| c. I get support from my friends and neighbors | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| d. My family has accepted my illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| e. Family communication about my illness is poor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| f. I feel close to my partner (or the person who is my main support) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| g. Have you been sexually active during the past year? No _____ Yes _____ If yes, I am satisfied with my sex life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| h. Looking at the above 7 questions, how much would you say your SOCIAL/FAMILY WELL-BEING affects your quality of life? | 0 not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very much so |

Relationship with Doctor

| | Not at all 1 | A little bit 2 | Somewhat 3 | Quite a bit 4 | Very much 5 | | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---|---|---|---|---|--------------------|
| a. I have confidence in my doctor(s) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| b. My doctor is available to answer my questions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| c. Looking at the above 2 questions, how much would you say your RELATIONSHIP WITH YOUR DOCTOR affects your quality of life? | 0 not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very much so |

Emotional Well-Being

| | Not at all 1 | A little bit 2 | Somewhat 3 | Quite a bit 4 | Very much 5 | | | | | | |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---|---|---|---|---|--------------------|
| a. I feel sad | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| b. I am proud of how I'm coping with my illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| c. I am losing the fight against my illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| d. I feel nervous | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| e. I worry about dying | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| f. I worry that my condition will get worse | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| g. Looking at the above 6 questions, how much would you say your Emotional WELL-BEING affects your quality of life? | 0 not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very much so |

Functional Well-Being

| | Not at all 1 | A little bit 2 | Somewhat 3 | Quite a bit 4 | Very much 5 | | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---|---|---|---|---|--------------------|
| a. I am able to work (include work at home) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| b. My work (including work in home) is fulfilling | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| c. I am able to enjoy life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| d. I have accepted my illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| e. I am sleeping well | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| f. I am enjoying the things I usually do for fun | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| g. I am content with the quality of my life right now | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| h. Looking at the above 7 questions, how much would you say your Functional Well-Being affects your quality of life? | 0 not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very much so |

Additional Concerns

| | Not at all 1 | A little bit 2 | Somewhat 3 | Quite a bit 4 | Very much 5 | | | | | | |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|---|---|---|---|---|--------------------|
| a. I have been short of breath | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| b. I am self-conscious about the way I dress | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| c. My arms are swollen or tender | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| d. I feel sexually attractive | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| e. I have been bothered by hair loss | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| f. I worry about the risk of cancer in other family members | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| g. I worry about the effect of stress on my illness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| h. I am bothered by a change in weight | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| i. I am able to feel like a woman | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | | | | | | |
| j. Looking at the above 9 questions, how much would you say your ADDITIONAL CONCERNS affects your quality of life? | 0 not at all | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 very much so |

Your Health

| | Excellent 3 | Very Good 2 | Good 3 | Fair 4 | Poor 5 |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 15. In general, would you say your health is: | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

16. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Check an answer for each activity)

| | HOW LIMITED YOU ARE | | |
|--|-------------------------------|-------------------------------|-------------------------------|
| | Not at all | A little | A lot |
| a. <u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | 3 <input type="checkbox"/> |
| b. Lifting or carrying groceries | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Climbing <u>several</u> flights of stairs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Walking <u>several</u> blocks | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

17. During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health:

- a. Accomplished less than you would like 1 ☐ Yes 2 ☐ No
- b. Were limited in the kind of work or other activities 1 ☐ Yes 2 ☐ No

18. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of emotional problems (such as feeling depressed or anxious):

- a. Accomplished less than you would like 1 ☐ Yes 2 ☐ No
- b. Didn't do work or other activities as carefully as usual 1 ☐ Yes 2 ☐ No

19. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

- 1 ☐ Not at all 2 ☐ A little bit 3 ☐ Moderately 4 ☐ Quite a bit 5 ☐ Extremely

20. During the past 4 weeks, how much of the time has your physical health or emotional problems limited your social activities (like visiting with friends, relatives, etc.)?

- 1 ☐ All the time 2 ☐ Most of the time 3 ☐ Some of the time 4 ☐ A little of the time 5 ☐ None of the time

21. For EACH of the following questions, please CHECK the answer that comes closest to the way you have been feeling and how things have been with you during the past 4 weeks.

| How much of the time during the <u>past 4 weeks</u> : | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | 1 | 2 | 3 | 4 | 5 | 6 |
| a. Have you felt calm and peaceful? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Did you have a lot of energy? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Have you felt downhearted & blue? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Have you felt very anxious or nervous? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

22. Check the box for each statement which best describes how often you felt or behaved this way during the past week

| During the <u>past week</u> : | Rarely or None of the Time (Less than 1 Day) 0 | Some or a Little of the Time (1-2 Days) 1 | Occasionally or a Moderate Amount of Time (3-4 Days) 2 | Most or All of the Time (5-7 days) 3 |
|---|---|---|---|--|
| a. I was bothered by things that usually don't bother me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I did not feel like eating; my appetite was poor | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. I felt that I could not shake off the blues even with help from my family or friends | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I felt that I was just as good as other people | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. I had trouble keeping my mind on what I was doing | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. I felt depressed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. I felt that everything I did was an effort | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. I felt hopeful about the future | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i. I thought my life had been a failure | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j. I felt fearful | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| k. My sleep was restless | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| l. I was happy | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| m. I talked less than usual | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| n. I felt lonely | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| o. People were unfriendly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| p. I enjoyed life | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| q. I had crying spells | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| r. I felt sad | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| s. I felt that people disliked me | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| t. I could not get going | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

SOCIAL SUPPORT

23. People sometimes look to others for help, friendship, or other types of support. Next are some questions about the support that you have. How often is each of the following kinds of support available to you if you need it?

| | None of the time 1 | A little of the time 2 | Some of the time 3 | Most of the time 4 | All of the time 5 |
|--|-----------------------------|---------------------------------|-----------------------------|-----------------------------|----------------------------|
| a. Someone you can count on to listen to you when you need to talk | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Someone to give you good advice about a problem | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Someone to take you to the doctor if you need it | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Someone to help you understand a problem when you need it | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Someone to help with daily chores if you are sick | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Someone to share your most private worries and fears | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Someone to do something fun with | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Someone to love you and make you feel wanted | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

24. How many relatives and friends do you have that you feel close to (feel at ease with, can talk to about private matters, can call on for help). (Check one box for relatives and one box for friends.)

| | Relatives | Friends |
|------------|-----------|---------|
| None | | |
| 1 or 2 | | |
| 3 to 5 | | |
| 6 to 9 | | |
| 10 or more | | |

25. Is this more or fewer than before your breast cancer diagnosis?

- 1 ☐ More relatives/friends than before diagnosis
- 2 ☐ Fewer relatives/friends than before diagnosis
- 3 ☐ Same number of relative/friends always had

27. How much does your breast cancer and its treatment currently interfere with different aspects of your life? CIRCLE the number that best describes your present life situation.

If an item is not applicable, circle number 1 (one) to indicate that this aspect of your life is not affected very much. *Please do not leave any item unanswered.*

| | Not Very Much | | | | | Very Much | |
|--|---------------|---|---|---|---|-----------|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| a. Health | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| b. Diet (e.g. The things you eat and drink) | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| c. Work | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| d. Active recreation (e.g. Dancing, sports) | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| e. Passive recreation (e.g. Reading, listening to music) | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| f. Financial situation | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| g. Relationship with spouse or partner | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| h. Sex life | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| i. Family relations | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| j. Other social relations | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| k. Self-expression/self-improvement | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| l. Religious expression | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| m. Community and civic involvement | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| n. Planning for the future | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

OVERALL SATISFACTION

28. Overall, how would you rate the following aspects of your breast cancer care at Kaiser Permanente:

| | Poor | Fair | Good | Very Good | Excellent | Does not Apply |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | 1 | 2 | 3 | 4 | 5 | 6 |
| a. Your care before surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Your care in the hospital for surgery | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Your care during chemotherapy or Tamoxifen | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Your follow-up care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. The amount of information you received | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. The amount of emotional support you received | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Thank you for completing the questionnaire.

Please return it in the pre-addressed, postage-paid envelope to:

Carol Somkin, PhD, Division of Research, Kaiser Permanente,
P.O. Box 12916 Oakland, CA 94604-9921

Anything Else?

Is there anything else you would like to tell us about your breast cancer experience? If so, write your comments here.

[illegible]